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ABSTRACT

This edition of the newsletter of the National Information Center for Handicapped Children and Youth describes the actions that are necessary to prepare students to achieve and maintain independence and highlights aspects of the roles of parents, professionals, and the young people themselves in transition planning. Brief articles have the following titles: "Transition--The Roles of Parents, Students, and Professionals"; "The Role of the Young Person--Achieving Independence"; "The Role of Parents--Launching the Young Person"; "How Professionals Can Help Young People with Disabilities Make the Transition to Work"; and "Action Issues." Twenty-seven references are cited. (CB)

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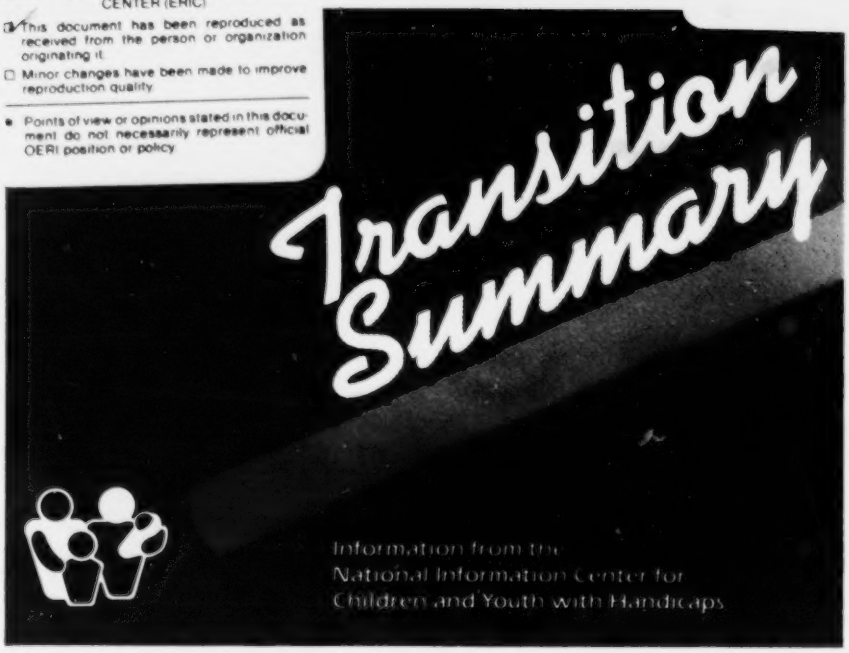
TRANSITION—The Roles of Parents, Students, and Professionals



TRANSITION SUMMARY #4 1987

People with disabilities are much more likely to be unemployed than nondisabled people. This disturbing fact has a far-reaching impact and is one of the truest generalizations that can be made about people with disabilities as a group.

A recent survey conducted for the ICD—International Center for the Disabled—and the National Council on the Handicapped by Louis Harris and Associates confirmed the 1983 estimate by the U.S. Civil Rights Commission that the majority of American adults with disabilities were unemployed (ICD Survey of Disabled Americans, 1986). The Harris Poll, as it is now known, provided some alarming insights into the lives of people with disabilities, not the least of which is that fully two thirds of all Americans with disabilities between the ages of 16 and 64 are not working. Moreover, only one in four works full-time, and another 10% work part-time.

There are many forces at work which contribute to this situation. In their landmark report to the President and the Congress, *Towards Independence*, the National Council on the Handicapped listed several barriers to employment over and above the scarcity of effective transition planning affecting persons with disabilities from all age groups who are seeking employment. They are:

- Attitudes that cause or contribute to employers' discrimination against persons with disabilities;
- Physical and communication barriers in work sites and transportation facilities; and
- Lack of appropriate training opportunities for people with disabilities.

Sarkees and Scott (1985) identified two others:

- A prevalence of attitudinal barriers among people with disabilities including low self-esteem, low expectations, and lack of understanding of the resources available to them; and
- Barriers in the service system itself—duplicative and confusing services, little or no interagency communication, and poorly trained professional personnel.

Two government agencies, the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS), and the U.S. Department of Health and Human Services, Administration on Developmental Disabilities (ADD), have taken a leadership role in the effort to make provision of effective transition services to young people with disabilities a major national priority. Their goal is to ensure that the young people with disabilities who are attending our nation's schools are not stymied by obstacles that have traditionally kept persons with disabilities from becoming employed. This new effort is unique in that it includes individuals who are severely and multiply disabled who have in the past been excluded from vocational programs.

Wehman (1985) defines transition as a process which seeks to "establish and implement a plan for either employment or additional vocational training of handicapped students." The process "must involve special educators, vocational educators, parents and/or students, and adult service system representatives and possibly an employer" (p. 114). Like other definitions of transition, Wehman's definition stresses the need for collaborative planning and the importance of employment as a goal for young people with disabilities. The purpose of this issue of *Transition Summary* is to describe the actions that are necessary to prepare students for the struggle to achieve and maintain independence throughout their lives, and to highlight important aspects of the roles of parents, professionals, and the young people themselves in transition planning.

The Role of the Young Person—Achieving Independence

Most of the writing on transition has focused on the role of parents and professionals. By comparison, little attention has been given to the role young people themselves must play in the transition process. And yet, involving young people in making decisions about their own lives is extremely important. If a young person has had a say in making plans for the future, he or she is more likely to feel a strong commitment to making those plans work.

"True advocacy involves fervor and depth of feeling...doing much more than is done routinely or would be found to be routinely acceptable."

All too often decisions are made *for* rather than *with* young people with disabilities. Turnbull and Turnbull (1985) have suggested several reasons for this tendency. They noted that special educators have tended to emphasize remediation and to deemphasize independence in the education of children with disabilities. Consequently, they have often overlooked the need to build self-esteem and to give students experience in making choices. There are several other reasons for the limited participation of young people in planning for their future. Sometimes the nature of young people's disabilities makes it difficult for them to be involved in making decisions about their future. Young people may have trouble communicating their ideas or thinking through their feelings to the point where they can identify goals for themselves. Because their disabilities may make them dependent on others, they may not have had much experience in making their own decisions.

Taking Charge of Your Life (1980), a guide designed to assist teenagers with disabilities to achieve independence, provides some interesting insights into the steps young people need to take to become more self-directing. The work was authored, in part, by persons who are disabled and reflects their experience in growing up with a disability. The Center for Independent Living (Berkeley, California), which collaborated with Closer Look in publishing this document, is one of 327 independent living centers (ILCs) located in communities throughout the country. ILCs provide persons with disabilities services which enable them to live independently. (Readers interested in obtaining a list of ILCs in their state should write the National Information Center for Children and Youth with Handicaps, Box 1492, Washington, DC 20013.)

Taking Charge of Your Life makes the following suggestions to young people with disabilities:

> You probably have questions about your disability and how it will affect your future. You should feel free to share your doubts with your parents and other family members and ask them about how your disability may affect your future. Unanswered questions and unresolved fears can become an obstacle to achieving independence.
>
> Though you may be forced to be more dependent than you would like to be, it is important to keep testing the limits of your abilities and to keep trying to do more and more for yourself.
>
> Be creative in finding other ways of doing tasks made more complicated by your physical limitations. Sometimes this can be done by adapting the physical surroundings or by using devices like communication boards or specially designed clothing.
>
> Consult other persons with the same disability for information. This can be an important source of information on creative solutions to common problems.
>
> You need to plan carefully to achieve independence. Knowing your preferences, your strengths, and your weaknesses, and exploring a variety of options are important steps in planning.

Copies of *Taking Charge of Your Life* can be obtained by writing the National Information Center for Children and Youth with Handicaps, Box 1492, Washington, DC 20013.

But making a plan is only the first step. Like everyone else, young people with disabilities will be presented with obstacles that they will have to overcome before they can put their decisions into effect. Overcoming obstacles will require them to become their own advocates. It is only in the last few years that professionals and parents have recognized that self-advocacy is an important skill for persons with disabilities. And yet, there is no widely accepted definition of the term. Apolloni (1984) refers to self-advocacy in terms of the efforts of people with disabilities to get service providers to respond to their needs. Varela (1986) defines self-advocacy as "running risks, challenging rules and acquiring resources" (p. 245). She adds that this definition is not universally accepted. Williams and Shoultz (1982) observe that "True advocacy involves fervor and depth of feeling . . . doing much more than is done routinely or would be found to be routinely acceptable" (p.88). Each of these authors emphasizes that self-advocacy can only be understood by examining how it is practiced by persons with disabilities. Harrington (1985) portrays the day-to-day reality of self-advocacy in his description of Gary and Maureen Poe, a couple with developmental disabilities who live in a suburb of Washington, DC. A large portion of the article deals with Gary Poe's determined efforts to find a job. Without using the term "self-advocacy," Harrington captures the essence of Poe's struggle to live with independence and dignity:

> He (Poe), is after all slow—clinically slow . . . So he fights not only his limitations, but also the fears of his father and in-laws, the cynicism of embittered friends who are themselves slow, and the prejudice of bosses, the guaranteed disability paycheck that can sap ambition, and, sometimes even the attitude of counselors and teachers assigned to help him. Through fear and good intentions they conspire to keep Poe a child forever. The catch is Poe *does* need help. He resists, however, when the price is his dignity. About that, he is very smart. (p.7).

The growing realization of the importance of self-advocacy has led to efforts to provide training in self-advocacy to persons with disabilities, particularly those making the transition from school to work. One example of this kind of effort is the Self-

Advocacy Training Project (SATP). Disabled in Action of Baltimore, a self-advocacy group made up of people with a variety of disabilities, Johns Hopkins University, and the Maryland Disability Law Center are collaborating in providing instruction to young people who are making the transition from school to work. The project establishes local groups of self-advocates throughout the state of Maryland. These groups provide information, referral, instruction, and self-advocacy technical assistance to transition age youth. Readers wishing to learn more about SATP should write:

Dr. Martin Gould
Disabled in Action of Baltimore,
3000 Chestnut Ave., Suite 204,
Baltimore, MD 21211.

The movement to promote greater self-advocacy has not been limited to persons with physical disabilities. People First and United Together are two self-advocacy groups founded by persons with mental retardation and other developmental disabilities. Participation in these groups provides members with an opportunity to learn self-advocacy skills from persons with similar disabilities and to provide a forum for expressing personal concerns and receiving emotional support. Readers interested in learning more about these organizations should write:

United Together, 348 Haworth,
University of Kansas,
Lawrence, KS 66045

People First International
P.O. Box 12642, Salem, OR 97309
(503) 378-5143

In addition, the Association for Retarded Citizens of the United States has published a directory of local self-advocacy programs. Readers may obtain a copy of this directory by writing the Association for Retarded Citizens of the United States, 2501 Avenue J, Arlington, TX 76006.

The Role of Parents—Launching the Young Person

In a sense, the role of the parents of a young person with a disability is essentially the same as it is for the parents of any other young person. Both are preparing their son or daughter to be independent and self-supporting individuals. However, because of the obstacles a young person with a disability is likely to encounter, his or her transition may have to be more carefully planned and more deliberately fostered.

Anderson, Beckett, Chitwood, and Hayden (1985) and Moon and Beale (1984) have described the different aspects of the roles of parents in the transition of a young person with a disability. Anderson and her colleagues have identified seven roles for parents in the transition process. The list includes:

1. Parents as Advocates for Career Education in School Programs. Career education makes children aware of the variety of different occupations that exist and prompts them to think of themselves in relation to different career options.

Phelps, Chaplin & Kelly (in press) describe career education as part of the larger process of career development. They state:

> *"Career awareness/orientation* should familiarize the students with all types of careers while promoting an awareness of themselves in relation to different career options. This stage typically begins in the late elementary years and early junior high school. Both in school and at home teachers and parents need to stress: the importance of work, the broad range of work and employment opportunities available, the relationship among different types of work (e.g. job ladders within a company, how workers in professions employ support staff in other occupations), and the personal and economic benefits derived from different types of work. Parents and other relatives can assist with the process of increasing career awareness by telling the young person about their own job, by describing what is involved in various occupations in the community, by using local newspapers, magazines, television, and movies to stimulate discussion of a variety of careers, and by encouraging children to explore hobbies which use skills and tools related to occupational interests."

2. Parents as Providers of Unique Information. Parents can provide valuable information on their child's personal traits, interests, aptitudes, and behaviors related to success on the job. Unfortunately, because parents often do not have confidence in their views about their children's abilities, they are reluctant to tell professionals at Individualized Educational Program (IEP) meetings and transition planning meetings what they know about their children.

Anderson and her colleagues suggest that parents keep a detailed record of their observations so that it can be shared with professionals as part of the transition planning process.

3. Parents as Role Models. Parents can have a powerful impact on young people's perception of work. All too often, young people with disabilities are led to believe, by the way they are treated at school and at home, that it is normal for them to be dependent. Parents need to make a conscious effort to impress upon their children that they can and will have jobs and become independent. Helping young people with disabilities develop appropriate behaviors is related to promoting positive attitudes towards work. Moon and Beale (1984) make several suggestions concerning the parents' role in developing appropriate behavior, including parents assigning specific duties to their child around the home, and emphasizing good grooming, physical fitness, and good social and communication skills.

4. Parent as Case Managers. Plans for transition services are not self-executing. Parents will need to follow carefully the implementation of transition plans and suggest, remind, confirm, and check up to make sure that the good intentions of agreements and collaborative efforts between various agencies are fully met. The task of parents may be complicated by the fact that a young person's need for services may extend beyond his/her school years. Unlike a free appropriate public education which is guaranteed by Public Law 94–142,

there is no right to services for young adults with disabilities. Likewise, there is no single agency responsible for providing services.

5. Parents as Program Advocates. The full range of services needed for transition is not yet available in most communities. Some school districts still do not provide career and vocational education programs to students enrolled in special education programs. Not all communities have available the full range of employment options for persons with disabilities, including supported work. Consequently, there will continue to be a need for parents and young people themselves to work with service providers, employers, and policy makers to increase the availability of employment options.

6. Parents as Risk Takers. Parents are often ambivalent about their son or daughter becoming more independent. They may know that letting go is the best thing, but actually allowing a young person with a disability to take the risks that go with independence may be hard. As Lotte Moise (1986) observed:

> We parents tend to be of divided heart as we prepare our offspring for a future without us. As group advocates we fight like tigers for our cubs' right to education, treatment and habilitation. As individual mamas and papas we often act more like kangaroos who keep their young ones in a protective body pouch . . . It is sometimes difficult to let our children take risky steps towards independence (p.3).

Anderson and her colleagues suggest that part of the ambivalence of parents may be the result of the tendency of professionals to overemphasize their children's deficits and pay little attention to what they are able to do for themselves. The authors believe that involving parents in planning for their children's transition to work and independence provides an opportunity for parents to become more confident of their children's abilities. It is important, however, that professionals address the realistic concerns of parents about the services that will be in place to support young people with disabilities in maintaining their independence.

7. Parents as Financial Planners. Quite often parents and young people with disabilities are faced with a dilemma caused by the fact that eligibility requirements for financial assistance programs create disincentives for persons with disabilities to go to work. A typical situation might involve choosing between accepting a minimum wage job with no medical benefits, which would lead to the loss of eligibility for Supplemental Security Income and Medicaid, or continuing to stay at home with a daily routine lacking in stimulation, opportunities for growth, and the satisfaction that work provides. Decisions of this type involve balancing the need for financial security and the desire for independence. Professionals can help parents find accurate information about the eligibility requirements of government programs and information about other means for protecting the young person's long-term interests, including wills, trusts, and guardianship. When parents have the necessary information, they can make informed decisions about the financial future of their son or daughter.

How Professionals Can Help Young People with Disabilities Make the Transition to Work

Professionals in schools and in agencies serving adults with disabilities have a role to play in helping young people with disabilities to make the transition from school to work. This role includes promoting independence; ensuring provision of an appropriate education, including placement in the least restrictive environment; and coordinating the services necessary for effective transition.

Promoting Independence

In the past when special educators and others concerned with the needs of children with disabilities have thought about independence they have usually referred to the ability of young people with disabilities to perform necessary physical tasks without assistance and the ability to separate themselves psychologically from parents, teachers, and other caregivers. However, as the transition from school to work has come into focus as a goal for young people with disabilities, professionals have begun to realize that the ability to make choices is an extremely important and neglected dimension of independence.

Turnbull and Turnbull (1985) discuss five strategies that can be used for developing the capacity to make decisions:

1. Providing Opportunities for Personal Life Planning—involves the student systematically exploring his or her identity, aspirations, capabilities, and goals.
2. Instruction in Problem Solving—teaches students to pinpoint and define problems, generate and evaluate alternatives, select the preferred alternative, take action, and evaluate the consequences of their actions.
3. Training in Choice-Making Values and Skills—provides information on values, legal rights, communication skills, and assertiveness.
4. Participation by the Student in Individualized Education Program Conferences—gives the student an opportunity to participate in decision making about his or her own educational program. The regulations implementing Public Law 94–142 allow students to participate in IEP meetings "as appropriate." In practice, students seldom participate, although studies of such participation have proven that it can be quite valuable.
5. Involvement in Self-Advocacy Groups—provides another means of teaching consent and choice skills.

The responsibility for promoting independence should be shared by professionals, parents, and young people themselves. It's not a goal which can be attained separately from other goals such as development of academic abilities, self-care skills, and social skills. Professionals should be striving to provide services in an atmosphere where children with

disabilities are imprinted from their earliest years with the assumption that they will become self-directing and self-supporting adults.

Providing an Appropriate Education

An appropriate education is one that prepares students to live independently and prepares them for employment. Providing services in the Least Restrictive Environment is an important part of such an education. Taylor, Biklen, and Searl (1986) describe a Least Restrictive Environment as one in which:

1. Children with disabilities are taught in the same school they would attend if they were not disabled.
2. Decisions concerning a child's educational program are based on that child's needs; that is, not all children with the same disabilities are placed in the same programs. Each child is educated in the setting appropriate to that child's individual needs.
3. The placement decision is made following the drawing up of an individualized educational program (IEP). Based on the educational and related services a child needs, a decision is made jointly by parents and school officials on where the child is placed.
4. Whenever possible, children with disabilities are taught in regular classes with their nondisabled peers.
5. Special services such as physical and occupational therapies, speech and language training, and instruction in sign language or braille are provided at regular schools.
6. Children who cannot be fully integrated are included in regular classes to the greatest extent possible.
7. Positive attitudes towards students with disabilities and social integration are actively promoted.

Opportunities for vocational education are another part of an appropriate education leading to successful transition. Differences in the severity of disabilities require different approaches be taken to vocational education. Phelps, Chaplin, and Kelly (in press) describe three phases of vocational education for students with mild and moderate disabilities:

1. Career Awareness and Orientation— includes activities designed to familiarize students with all types of careers while promoting an awareness of themselves in relation to different career options. During this stage professionals and parents need to stress that work is an important part of each person's life.
2. Career Exploration— provides young people during the initial years of high school with opportunities to learn by doing "hands-on" activities. Introductory vocational courses help young people to become familiar with the general nature of work in such fields as business, industry, agriculture, health, etc. These courses provide opportunities to work on practical projects, test manipulative skills, apply general education, and learn more about the field through guest lecturers and site visits.

3. Career Preparation—usually takes place during the later years of high school or after entering post-secondary education. Training during this phase assists the student who has already made a career choice and is ready to prepare for entering work in a certain field or occupation.

Bellamy, Rose, Wilson, and Clarke (1986) suggest that a different approach to vocational training should be used with students who have more severe disabilities. The authors discuss two alternative strategies. The first, the *specific job training strategy*, involves identifying an appropriate job in the community. The job's requirements are then analyzed and the student is taught them, ideally at the work site itself. There are several advantages to this strategy: 1) It provides specific work skills; 2) It often leads to immediate placement of the student and allows for integrated job exeriences; and 3) It minimizes the need for generalization of skills which is often very difficult for individuals with severe disabilities.

The other alternative is the *job cluster strategy*. This involves identifying a relatively broad occupational area, such as maintenance, woodworking, or electronics which would contain several discrete jobs sharing common elements or features. The student learns sample tasks and procedures and then learns to adapt them to the various untaught tasks within the cluster.

The cluster strategy provides the student with a degree of flexibility in job selection, and consequently, a likely increase in successful mobility between jobs. It also provides a much-needed framework for enhancing generalization of skills and increasing the variety of experiences and settings in which the student can learn.

Bellamy and his colleagues suggest that these strategies be used in the reverse sequence of the more traditional approaches of career awareness, prevocational training, and/or simulated work experience. Once the student gains specific job skills, the cluster model can be used to increase his/her repertoire of work skills and experiences. Then, attention can be given to developing career awareness and an understanding of how to make choices, which might open up additional employment options.

Coordinating Services for Effective Transition

Many young people with disabilities will need to obtain services from more than one agency in order to make a successful transition from school to work. The services required by a young person may include vocational training, residential services, and recreational programming. Without close coordination among agencies providing services to a young person, there is a serious prospect that the student and his or her family will be faced with the task of piecing together fragments of programs available to them from different agencies in their communities.

Coordination can take place at the program or system level. Elder (1979) states that "Program-level coordination results when various agencies integrate their efforts around administrative functions, organizational structures, or their individual programmatic thrusts and modify them as needed to ensure more coordination between their operations" (p. 193). Professionals attempting to improve coordination often face significant obstacles such as institutional inertia that favor the status quo, a preoccupation with the agency's self-interest or "turf", fear of having to change,

variation in client eligibility standards, differences in the terminology used by agencies, and the fragmentation of authority and responsibility within the service system.

One means of improving coordination is the development of formal plans for interagency coordination of transition services. Schwamm (1986) cites Audette (1980) on the elements required for successful interagency agreements on transition services. Among the elements recommended as essential to interagency cooperation are: use of common terminology, uniform forms, a single intake system, joint planning and administrative arrangements, and a common data base that allows agencies to share information with other agencies.

Action Issues

This paper has emphasized that the end product of the transition process is employment for young persons with disabilities. For this process to be successful, certain actions should be taken by young people with disabilities, their parents and family members, and the professionals who work with them. Consider the following:

1. What parents and professionals do to help young people is important; what young people do for themselves is absolutely crucial. Their attitude towards work, their ability to get along with others, their ability to communicate effectively and their possession of specific job skills are key elements that will enhance their chances for success in the transition process.

2. Parents, professionals, and the young person with disabilities need to think strategically about the young person's future. The essence of strategic thinking is choosing both long- and short-term goals and fitting one's actions to those goals.

3. The way in which professionals, parents, and young persons with disabilities play their roles cannot be reduced to a formula. The process for promoting transition is a new frontier. People working on any frontier need to be open to innovation, to experimentation, and to improvisation.

Those involved in the transition process may need information about alternatives in transition programming, names of local contacts who can help in identifying options within a community, and other types of information. The Office of Special Education Programs, U.S. Department of Education has funded two clearinghouses to provide information and support to parents, professionals, and others interested in the transition of young people with disabilities. For such information readers can contact either: National Information Center for Children and Youth with Handicaps (NICHCY), P.O. Box 1492, Washington, DC 20013, (703) 522-3332, or Higher Education and Adult Training for People with Handicaps (HEATH), National Clearinghouse on Post-secondary Education for Handicapped Individuals, One Dupont Circle, Suite 800, Washington, DC 20036 (202) 939-9320, (800) 544-3284.

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